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## Type 1 Diabetes in children

### Prevalence

There are approximately 29,000 children and young people with diabetes in the UK, of which about 26,500 have Type 1, 500 have Type 2 and 2,000 have an unrecorded diagnosis<sup>1</sup>. Type 1 diabetes is the leading cause of diabetes in children of all ages and the number diagnosed with the condition is rising by approximately 4% each year<sup>2</sup>. Although the peak age for diagnosis is between 10 and 14, the onset of the condition can occur at any age and an increasing number of younger children are being diagnosed. According to Diabetes UK, of those children who are newly diagnosed, about 25% are not diagnosed until they are in diabetic ketoacidosis (DKA) and this figure rises to 35% in children under 5 years<sup>3</sup>. DKA, abnormally high blood glucose levels resulting in the production of ketones and acidosis, can be fatal if left untreated, and is the leading cause of death in children with Type 1 diabetes.

### Early identification

Although Type 1 diabetes cannot be prevented, if it is properly identified, DKA can be avoided. An awareness of the symptoms of Type 1 diabetes is crucial, in particular amongst those working in primary care since the GP practice is often the first port of call for parents with a child who is ill. The main symptoms of Type 1 diabetes are:

- Feeling very thirsty;
- Passing excessive amounts of urine, especially at night;
- Extreme tiredness and lethargy;
- Weight loss and muscle wasting despite increased appetite.

It is important that those health care professionals working in primary care are constantly aware of, and alert to, the fact that a diagnosis of Type 1 diabetes is a realistic possibility in children, which necessarily means being familiar with the clinical features of the condition. Cases of missed or delayed diagnosis are frequent occurrences with approximately 30% of children with newly diagnosed Type 1 diabetes having to make at least one visit to the GP prior to being accurately diagnosed<sup>4</sup>. This suggests that the condition is still not widely recognised by healthcare professionals working in primary care. However, whilst the classic symptoms of Type 1 diabetes listed above are becoming increasingly well known, it is often the case that a child presents with other early indicators of the condition that are non-specific and which make an accurate diagnosis more problematic. This is especially the case for children under the age of 2 where the classic symptoms are not immediately obvious. The situation is further complicated by the fact that children may not necessarily display all the symptoms at the same time, symptoms may vary depending on the age of the child and the child may simply feel 'unwell'. Other less specific symptoms to look out for include:

- Bed wetting in a previously 'dry' child. This is the earliest indication of Type 1 diabetes, occurring in 89% of children over the age of 4<sup>5</sup>;
- Constipation. This occurs in about 10% of children under the age of 5 and is secondary to chronic dehydration<sup>5</sup>;
- Itchy skin rash or slow healing wounds;
- Genital itching;
- Discomfort or pain on passing urine;
- Blurred vision;
- Abdominal pain;
- Headache;
- Vomiting.

There are additional reasons why a diagnosis of Type 1 diabetes is often missed. These include: parents failing to mention symptoms (e.g. bedwetting); parents misinterpreting symptoms (e.g. lethargy, weight loss) as normal characteristics of children, especially those who are older; health care professionals failing to do a capillary blood glucose test on a child presenting with the symptoms of Type 1 diabetes, and, if a child has already developed DKA by the time they present at a GP practice, health care professionals misdiagnosing the condition as possible gastroenteritis, acute asthma or pneumonia.

To ensure children receive a quick diagnosis and early treatment, thereby reducing the number of children who are misdiagnosed or are not diagnosed until they are in DKA, Diabetes UK has recently launched its '4 Ts of Type 1 diabetes campaign'<sup>6</sup>. Everyone working with children and young people need to be aware of the 4 Ts and they should know what to do if they recognise them, in terms of diagnosis and onward referral.

#### Primary care

All of the above factors highlight the importance placed on health care professionals in primary care to take a thorough history of the child. It is worth noting that the majority of children diagnosed with Type 1 diabetes have no family history of the condition. If symptoms are indicative of Type 1 diabetes, it is imperative that a child does not leave the GP practice until a diagnosis has been made, or Type 1 diabetes as a possibility has been ruled out. Type 1 diabetes can be diagnosed with a single capillary blood glucose test and is always required, even after a urine glucose test. Guidelines report a random blood glucose concentration of  $>11.1\text{mmol/l}$  as a diagnostic criteria for diabetes<sup>7</sup>, which can be confirmed with a laboratory testing of blood glucose when the child arrives in hospital. A child should not wait for a fasting blood glucose test as DKA may develop in the intervening period. Rather, if they are suspected of having Type 1 diabetes, a child should be referred immediately to secondary care and a specialist, multidisciplinary (MDT) paediatric diabetes team for confirmation of diagnosis and management of the condition<sup>8</sup>.

The importance of the MDT (doctors, diabetes specialist nurses, dietitians and psychologists) in treating and educating children and parents about the management of Type 1 diabetes cannot be underestimated, since it is a highly complex medical condition that requires health care professionals to have a large number of clinical, educational, social and psychological skills. Children with Type 1 diabetes require insulin, which needs to be started immediately on the day of referral and members of the MDT are best placed to do this. Various insulin regimens may be adopted depending on the child's age, weight, developmental stage and cognitive ability, as well as the level of family support. An increasing number of diabetes centres are starting to use multiple injections and pump therapy, but other possible regimens include two or three injections per day of various combinations of insulin types. It is important that health professionals working in primary care are aware of the different insulin regimens and changing practices. Inevitably, for many families, after the initial shock and trauma of diagnosis there is a massive learning curve as they come to terms with the challenge of injections, blood tests, food values, lifestyle routine and a whole change in mind set. They have to adjust to what is a life-changing experience and in doing so the diabetes specialist nurse becomes the key point of reference for families. However, primary care teams, including practice nurses and GPs, can play their part in helping families adjust to the new diagnosis of Type 1 diabetes.

#### Role of nurses working in primary care

The National Service Framework (NSF) states that all nurses, wherever they work, should ensure that they know and can practice at least the basics of diabetes care<sup>9</sup>. Whilst it is essential that all primary health care professionals are educated in the symptoms and referral pathway for children suspected of Type 1 diabetes, practice nurses in particular are in an ideal position to do more than this, simply

because they work in the community and it is likely they will know the child who has been recently diagnosed. There may be issues around concordance, barriers to engagement with diabetes management and the mental and physical wellbeing of both the child and parents. Parents take their children to the doctors for a variety of non-diabetes related problems so this may provide a reasonable opportunity for nurses to discuss diabetes management and any problems that children and/or parents are experiencing, for example in relation to their insulin regimen, change in lifestyle, management at school, etc. In addition, there is the potential for nurses to gain a deeper insight into the emotional state of children and parents, particularly pertinent for parents of young children who are too young to understand their diabetes, and, therefore, the emotional and practical burden of responsibility for the day-to-day diabetes care falls on the parents. Practice nurses can support the family by listening to their concerns, offering advice and if appropriate, liaising with or referring families to their paediatric diabetes team or other specialist services.

## Conclusion

Nurses working in primary care cannot be expected to be knowledgeable about all aspects of paediatric diabetes care. However, they can play an important role, firstly, in ensuring children are accurately diagnosed and secondly, encouraging and supporting children and families to make healthy choices and improve the quality of their lives by avoiding complications associated with Type 1 diabetes. A child diagnosed with Type 1 diabetes faces a reduced life expectancy of up to 20 years and long-term complications if the condition is not carefully managed<sup>10</sup>. Therefore, it is incumbent upon all healthcare professionals to make Type 1 diabetes a priority and to work towards optimising the care of children. This necessarily means the provision of more training opportunities for practice nurses in Type 1 diabetes and improved communication and joint working between paediatric healthcare professionals and primary care teams.

## Box 1

### Signs and symptoms of Type 1 diabetes

An awareness of the symptoms of Type 1 diabetes is crucial, in particular amongst those working in primary care since the GP practice is often the first port of call for parents with a child who is ill. The main symptoms of Type 1 diabetes are:

- Feeling very thirsty;
- Passing excessive amounts of urine, especially at night;
- Extreme tiredness and lethargy;
- Weight loss and muscle wasting despite increased appetite.

Other less specific symptoms to look out for include:

- Bed wetting in a previously 'dry' child. This is the earliest indication of Type 1 diabetes, occurring in 89% of children over the age of 4<sup>5</sup>;
- Constipation. This occurs in about 10% of children under the age of 5 and is secondary to chronic dehydration<sup>5</sup>;
- Itchy skin rash or slow healing wounds;
- Genital itching;
- Discomfort or pain on passing urine;
- Blurred vision;
- Abdominal pain;
- Headache;
- Vomiting.

## Box 2

### Diabetes UK recommendations<sup>3</sup>

- Parents of children with any symptom of Type 1 diabetes should see a doctor straight away and insist on capillary blood glucose testing there and then
- Particular caution should be taken for children under 2 as they may not display the classic signs and symptoms of Type 1 diabetes
- All GPs, primary healthcare professionals, health visitors, school nurses and other non-specialist healthcare professionals to be educated in the symptoms and management of Type 1 diabetes
- All primary healthcare staff to have access to a blood glucose monitor and be educated in its use
- A capillary blood test to be taken immediately on any child presenting with any symptom of Type 1 diabetes. Waiting for a fasting blood glucose level is not appropriate and the HbA1c test should not be used to diagnose Type 1 diabetes in children
- Any child suspected of having Type 1 diabetes should have a same day referral to a specialist paediatric diabetes team for confirmation of the diagnosis and management

## Box 3

### The 4 Ts of Type 1 diabetes<sup>6</sup>

#### *Toilet*

Going to the toilet a lot, bed wetting by a previously dry child or heavier nappies in babies

#### *Thirsty*

Being really thirsty and not being able to quench the thirst

#### *Tired*

Feeling more tired than usual

#### *Thinner*

Losing weight or looking thinner than usual

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